

Alzheimer's Disease and People with Down Syndrome

A training for Everyone
Family Members and Support Staff

Developed With Funding Support from the Arizona Developmental Disabilities
Planning Council



alzheimer's  association®

Desert Southwest Chapter

800.272.3900
alz.org/dsw

Learning Objectives

- At the end of this training participants will be able to:
 - Describe Alzheimer's disease and the disease process
 - Explain how Alzheimer's disease impacts people with intellectual and developmental disabilities
 - Identify at least 3 strategies to provide effective supports

Aging and Alzheimer's disease

alzheimer's  association®

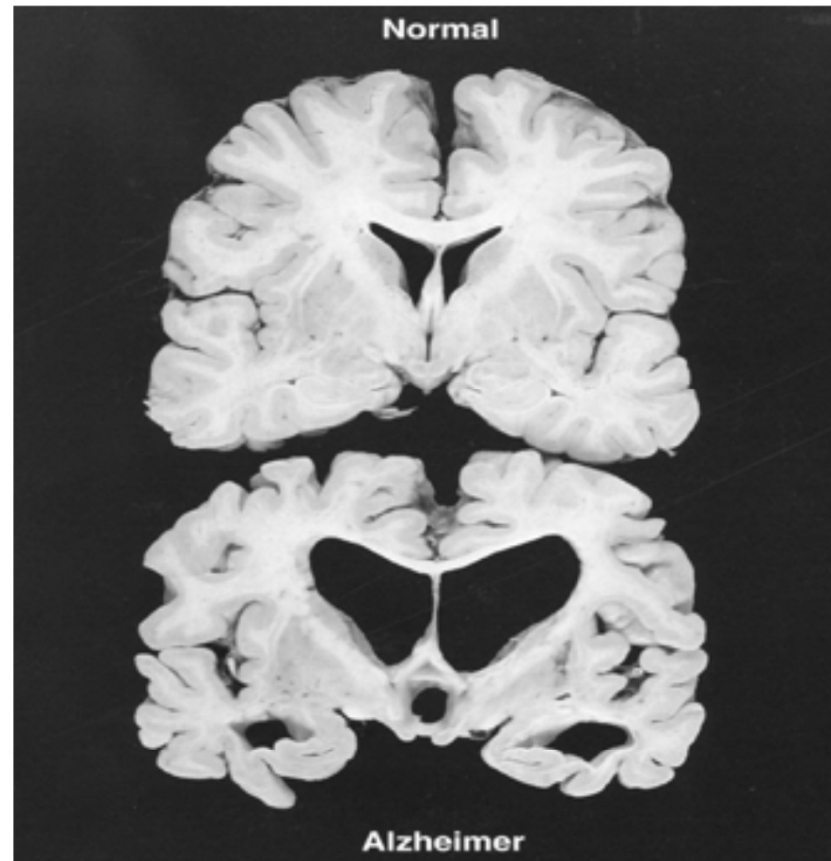
Desert Southwest Chapter

800.272.3900
alz.org/dsw

What is Alzheimer's Disease?

- A progressive, degenerative, neurological disease of the brain
- A steady decline in memory and intellectual functioning severe enough to interfere with everyday life
- It is not reversible

What does Alzheimer's look like?



alzheimer's  association®

Desert Southwest Chapter

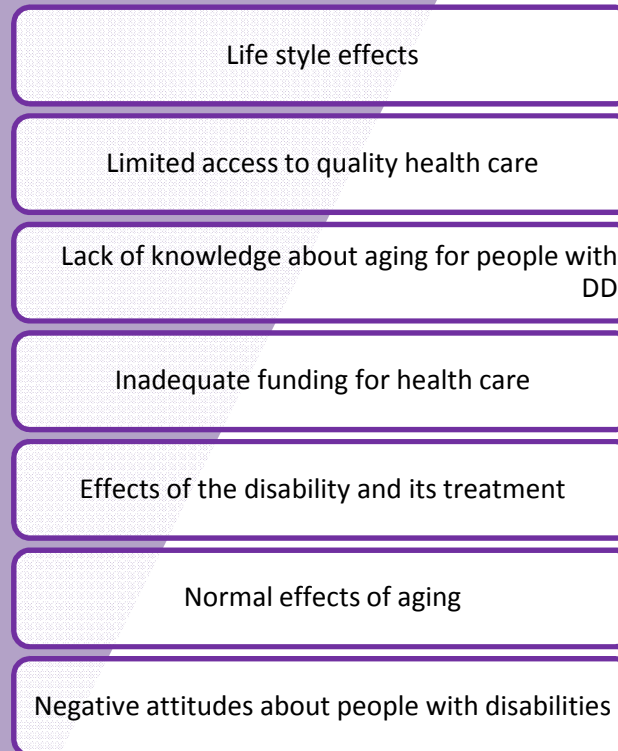
800.272.3900
alz.org/dsw

General Warning Signs

- **Memory changes**
- **Challenges in planning or problem solving**
- **Difficulty completing familiar tasks**
- **Confusion with time or place**
- **Trouble with visual or spatial relationships**
- **Problems with words**
- **Misplacing things**
- **Decreased or poor judgment**
- **Withdrawal from activities**
- **Changes in mood and personality**

Aging With a Developmental Disability

Results in decreased quality of life for the person with a disability



Intellectual Disabilities (ID) and Dementia

- Increased life expectancy in ID population result of constructive public policies, focus on health and better community support services
- Greater numbers of aging people are result of ‘baby boom’ cohort, and increased life expectancy including those with ID
- The population of persons with ID and dementia will double in the next twenty years.

Down Syndrome and Dementia

- It is estimated that 6% of adults with an ID will be affected by some form of dementia after the age of 60 (with the percentage increasing with age).
- There is a genetic propensity for adults with Down syndrome to develop early onset Alzheimer's disease.
- For adults with Down syndrome, studies show that at least 25% will be affected with dementia after age 40 and at least 50 to 70% will be affected with dementia after age 60.
- A significant percentage of the older ID population will be adults with Down syndrome, who usually make up about 10% of most ID providers' service populations of adults age 40 and older.

The Relationship of Alzheimer's Disease and Down Syndrome

- **Consequence of accelerated aging process**

Accelerated progression of disease in those with Down Syndrome

- **Overexpression of amyloid precursor protein** (integral membrane protein expressed in many tissues and concentrated in the synapses of neurons) **on chromosome 21 in both**

- **Acetylcholine** (organic molecule that acts as a neurotransmitter) **levels low in both Down syndrome and Alzheimer's patients**

- **Degeneration of the hippocampus** (plays important roles in the consolidation of information from short-term memory to long-term memory and spatial navigation) **in both**

How many people with down syndrome get Alzheimer's?

Percentage of people with Down syndrome who develop dementia at different ages:

Age percentage with clinical signs of dementia

30's	2%
40's	10-15%
50's	33%
60's	50-70%

Source: Neil, M. (2007). Alzheimer's dementia: What you need to know, what you need to do. Understanding intellectual disability and health. Accessed from <http://www.intellectualdisability.info/mental-health/alzheimers-dementia-what-you-need-to-know-what-you-need-to-do>.

Warning Signs for Adults with Down Syndrome/IDD

- Development of seizures
- Changes in personality
- Long periods of inactivity or apathy
- Hyperactive reflexes
- Loss of activity of daily living skills
- Loss of speech
- Disorientation
- Increase in stereotyped behavior
- Abnormal neurological signs

Warning Signs for Adults with Down Syndrome/IDD

- Changes in activities of daily living skills are noted most often
- Seizures may occur in individuals who have not had them in the past
- Cognitive changes may be present although they may not be apparent

Aging Issues that Mask Alzheimer's in Adults with Down Syndrome/IDD

- Visual and hearing impairments
- Thyroid disorders
- Depression
- Physical health problems
- Medication effects
- Nutritional deficiencies

Stages of the Disease

alzheimer's  association®

Desert Southwest Chapter

800.272.3900
alz.org/dsw

Stages of Alzheimer's Disease

Generally described as having three stages:

- Mild (early)
- Moderate (middle)
- Severe (late)

Changes in Adults with Mild to Moderate Developmental Disabilities

Early Stage

- Loss of activity of daily living skills
- Behavioral Changes
- Personality changes
- Development of seizures
- Slow movement or alertness

Changes in Adults with Mild to Moderate Developmental Disabilities

Early Stage (cont.)

- Disorientation to time and place
- Easily frustrated, loss of familiarity with activities
- Visual problems
- Apathy or inactivity
- Preference for familiar things

Changes in Adults with Mild to Moderate Developmental Disabilities

Middle stage

- Symptoms of early stage increase
 - ADL markedly deteriorate
- Confusion and frustration increased
- Sleep disturbances
- Changes in appetite

Changes in Adults with Mild to Moderate Developmental Disabilities

Middle stage (cont.)

- Recognition of self and others begins to decline
- Severe change in personality
- Restlessness, wandering
- Communication reduced

Changes in Adults with Mild to Moderate Developmental Disabilities

Late Stage

- Severe disorientation to time and place
- Difficulty swallowing
- Loss of speech
- Difficulty walking
- Incontinent

Changes in Adults with Mild to Moderate Developmental Disabilities

Late Stage (cont.)

- No longer recognizes family members
- Inability to survive without total care
- Death occurs most commonly from pneumonia and kidney failure

Changes in Adults with Severe to Profound Developmental Disabilities

- Socially withdrawn, reduced responsiveness
- Apathy
- Impaired attention
- Almost seem to be in a coma

Nonpharmacological Strategies For Support

- **Remember the four S's**
 - Maximize **Safety** and Limit the Risks
 - Promote **Structure** and Consistency
 - Enhance **Serenity** and Limit Confusing Stimuli
 - Nurture **Sanity** and Supports for All Caregivers

Pharmacologic Strategies

- For Depression and Anxiety and Psychosis and agitation
 - Continually re-assess effects of treatment
 - Avoid polypharmacy
 - Determine short and long term goals
 - Continually reassess response and need for medication(s)

Diagnostic Tools

- Focused medical and family history
- Physical exam and laboratory tests
- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities – DSQIID
 - Can be used by staff and families if they are worried an individual is developing dementia.
- Neuropsychological tests

Diagnostic Tools (cont.)

- Functional status exam – for disease progression
- Mental status exam (adapted for ID/DS)
- Assessment for delirium/depression
- Brain scans (CT or MRI)

Prepare for Appointments

- Gather pertinent information
- Know past pertinent medical history
- Always compare the person to who she or he has been throughout a lifetime, not to others of similar chronological age
- Different shifts and perspectives of team/family
- Symptoms as specific as possible, time of day, what behaviors, patterns, who is present
- Prioritize symptoms
- Share the information with advocate who will be going
- Know what recent therapies have been given and assessments and be prepared to discuss changes

Benefits of Early Diagnosis

- Manage symptoms of dementia
- Maintain daily activities to the extent possible and preserve quality of life
- Anticipatory guidance
- Help offset caregiver stress
- Maintain ‘aging-in-place,’ whenever possible and appropriate

Slide 29

CV1

Consider substituting Community Living and Person Centered Services

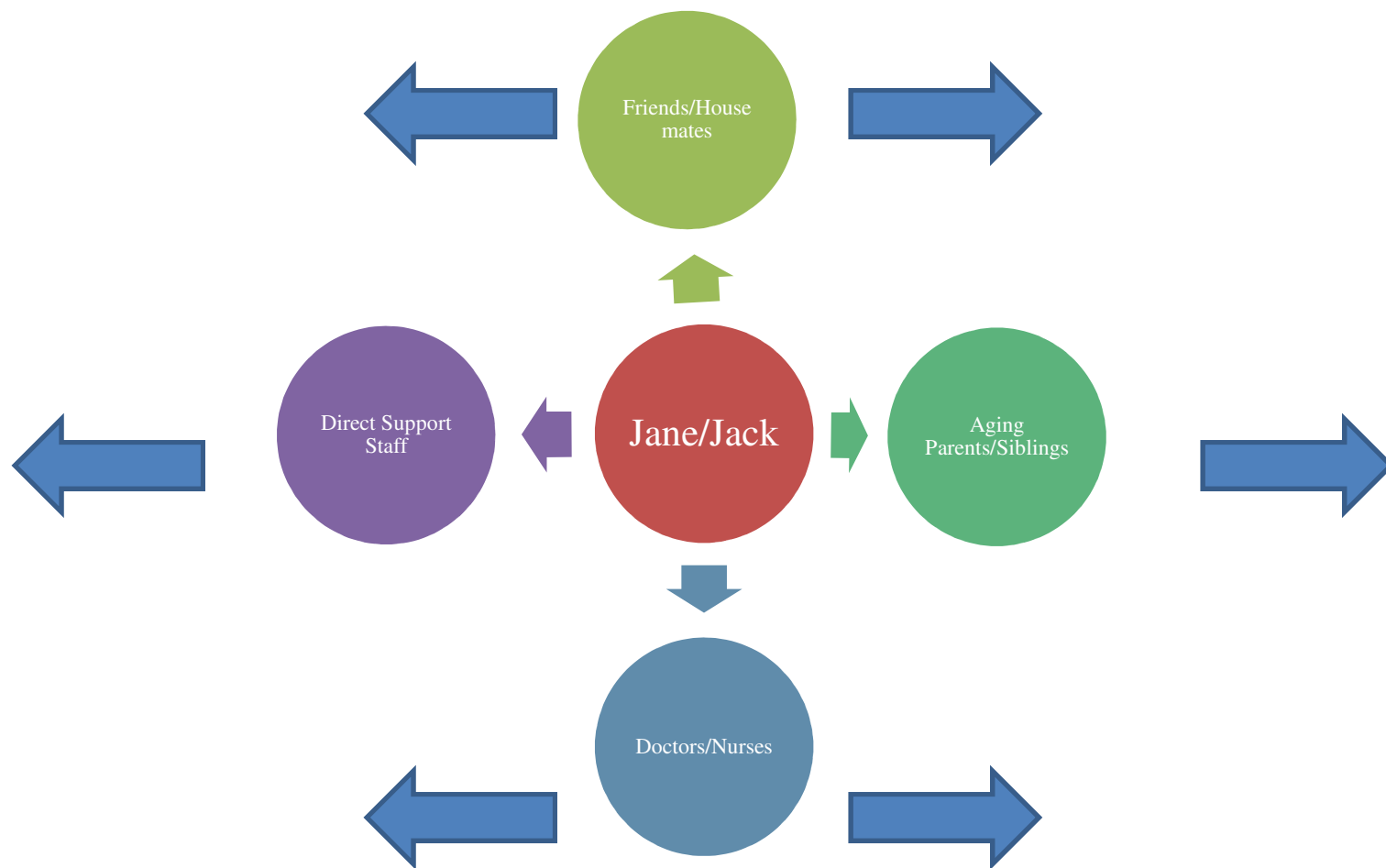
Cynthia Vargo, 7/22/2013

The Ripple Effect

Need to Create a Dementia Friendly Community With Dementia-capable Care for Everyone

Because dementia is a condition that lessens an individual's ability to self-direct and be left alone, long-term continued independent living is not an option

The Ripple Effect



What kinds of services are needed for aging people with ID and Dementia?

- Supports for continued living with families when available and appropriate
- Engaging activities in community settings
- Health reviews and surveillance
- Appropriate screening and assessments for aging-related conditions
- Health maintenance – nutrition and exercise
- Supports for ‘dementia-capable’ care in community care settings that can change as the disease progresses; including education and training

Edinburgh Principles

- Questions raised by various service providers organizations across the world
- Involved key international researchers and service providers in the field of aging and intellectual disabilities
- Edinburgh Working Group on Dementia Care Practices: University of Stirling (Scotland), the State University of New York at Albany (USA), and the University of Illinois at Chicago (USA)

Edinburgh Principles

1. Adopt an operational philosophy that promotes quality of life.
2. Affirm that individual strengths guide decision-making
3. Involve the individual and family in all planning and service
4. Ensure availability of appropriate diagnostic and service resources

Edinburgh Principles

5. Plan and provide supports to optimize remaining in the community
6. Ensure that people with developmental disabilities have access to the same dementia services provided to others in the population
7. Ensure that community planning involves focus on adults with developmental disabilities

‘Aging in Place’: Goals

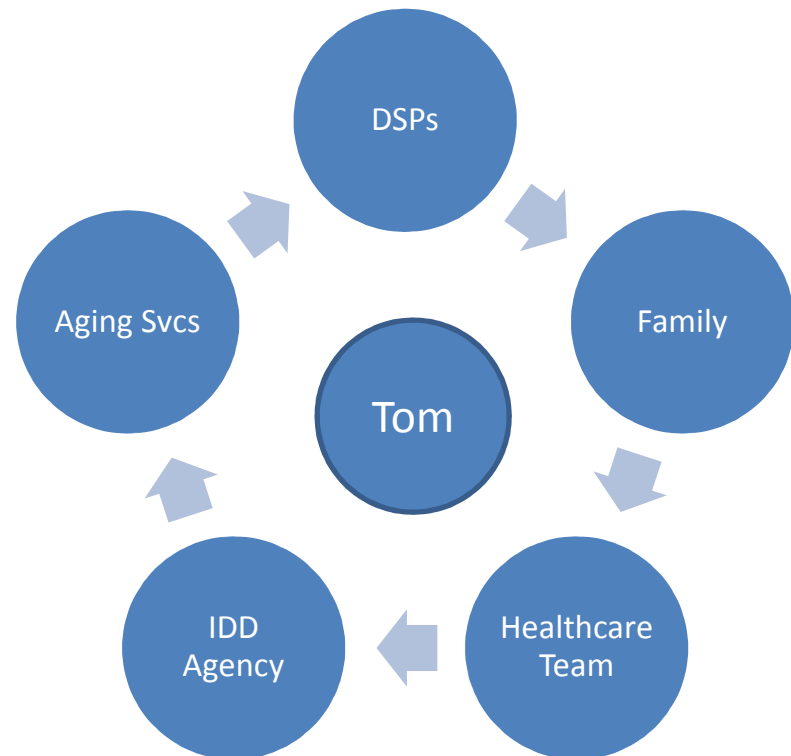
- What is ‘aging-in-place’ for people with ID and dementia and their families?
- What do we consider best practices?
- Supporting family caregivers
 - Recognize the challenges faced by the aging caregiver
 - Support sibling and parent care providers
- Change of care focus
 - Going from making gains to that of maintaining as much function as possible and dealing with eventual loss and decline
- Develop and emulate current models of care that anticipate the increasing support needs as dementia progresses

Addressing the dementia-related community care needs of adults with ID

- Diagnostic and intervention assistance
- Dementia care training for caregivers (family or staff)
- Support groups for caregivers (family or staff)
- Dementia capable community housing (group homes)
- Dementia capable day care programs and respite
- Health care and social supports

Team Approach to Care

- Improving outcomes
- Respect for need and opinions of team members
- Helps anticipate and prepare for decline
- Who is the team??



Care Management for Adults with Alzheimer's Disease and Down Syndrome

- Support the individual to feel safe and secure
- Emphasize maintaining abilities rather than teaching new skills
- Simplify routines and reduce choices
- Use patience and redirection and offer supportive care

Suggested Interventions

Early stage

- Routine and familiarity are important
- Continue activities with structure, more guidance and supervision
- Simplify directions
- Give multiple clues

Suggested Interventions

Middle Stage

- Create a calm environment
- Allow for rest periods
- Anticipate needs
- Simplify tasks
- Respond to the feeling behind the action

Suggested Interventions

Late stage

- Anticipate physical needs
- Consider palliative/comfort care
- Consider hospice care

Palliative and End of Life Care

- The realization that Alzheimer's disease progresses with increasing risks of health complications impacting one's lifespan
- Respecting one's wishes for level of care and quality of life
- Defining, anticipating, and preparing for end of life
- Appreciate how the impact is felt upon everyone around them
- Celebrating one's life

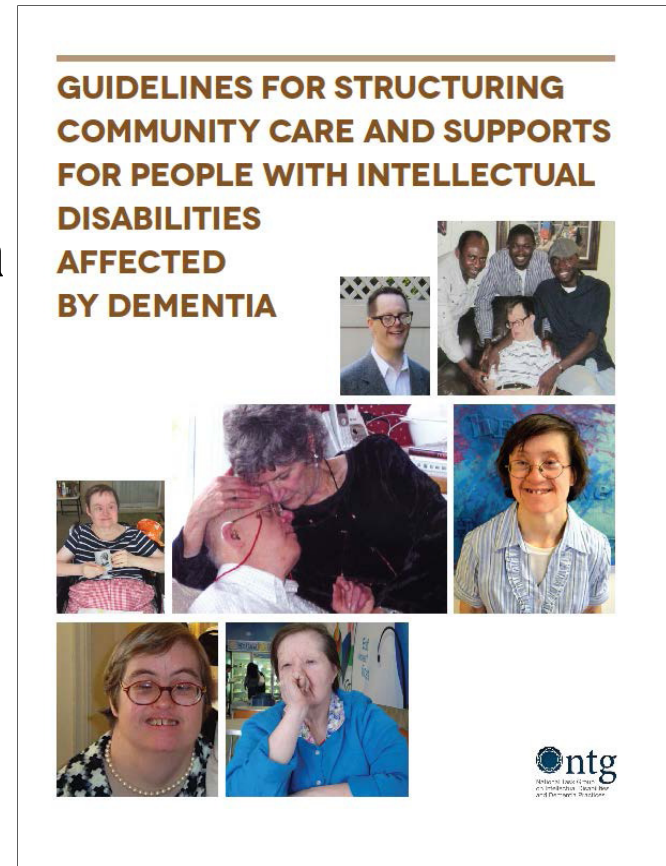
Where to get help/supports?

- Local Alzheimer's Association chapter
 - Alz.org/dsw
- National Alzheimer's Association website
 - Alz.org
 - www.alz.org/library/downloads/downsyndrome
- University of Illinois at Chicago website
- Dementia assessment clinics

Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia

**Journal of Policies and Practices in
Intellectual Disabilities**, Volume 10, Issue 1,
pages 1–24, March 2013
<http://aadmd.org/NTG>

Nancy Jokinen, Matthew P. Janicki,
Seth M. Keller, Philip McCallion ,
Lawrence T. Force, and the National Task Group on Intellectual Disabilities and
Dementia



alzheimer's  association®

Desert Southwest Chapter

800.272.3900
alz.org/dsw

Alzheimer's Disease Education and Referral (ADEAR) Centers National Institute on Aging

NIA-funded Alzheimer's Disease Centers (ADCs):

- ADCs conduct research to improve diagnosis and care and test treatments
- Help with obtaining diagnosis and medical management
- Opportunities to participate in research

Alzheimer's Disease Research Centers

The National Institute on Aging funds Alzheimer's Disease Centers (ADCs) at major medical institutions across the U.S. Researchers at these Centers are working to translate research advances into improved diagnosis and care for Alzheimer's disease (AD) patients while, at the same time, focusing on the program's long-term goal—finding a way to cure and possibly prevent AD.

Areas of investigation range from the basic mechanisms of AD to managing the symptoms and helping families cope with the effects of the disease. Center staff conduct basic, clinical, and behavioral research and train scientists and health care providers who are new to AD research.

Although each center has its own unique area of emphasis, a common goal of the ADCs is to enhance research on AD by providing a network for sharing new ideas as well as research results. Collaborative studies draw upon the expertise of scientists from many different disciplines.

For patients and families affected by AD, the ADCs offer:

- Diagnosis and medical management (costs may vary—centers may accept Medicare, Medicaid, and private insurance).
- Information about the disease, services, and resources.
- Opportunities for volunteers to participate in drug trials, support groups, clinical research projects, and other special programs for volunteers and their families.

Some ADCs have satellite facilities which offer diagnostic and treatment services and research opportunities in underserved, rural, and minority communities.

National NIA-funded AD resources are listed at the end of the directory.

For more information, contact any of the centers in the directory below. The directory is also available in [PDF format \(253K\)](#).

Find an Alzheimer's Disease Center (ADC): Click on a city name in the map below or browse the list of ADCs [by State](#).



Map labels include: Seattle, Portland, Sacramento, San Francisco, Los Angeles (2), Irvine, San Diego, Phoenix, Dallas, St. Louis, Kansas City, Chicago (2), Rochester, Madison, Pittsburgh, Boston (2), New York (3), Philadelphia, Baltimore, Lexington, Durham, Atlanta, Tampa.

News & Highlights

Publications

Research Centers

Clinical Trials

AD Library

Questions? Contact ADEAR

Call to talk to an Information Specialist:
1-800-438-4380 (toll-free)
Mon-Fri, 8:30 am-5:00 pm Eastern Time
or send an email to: adear@nia.nih.gov

Examples of Organizational Supports

- Administration on Community Living <http://www.hhs.gov/acl/>
 - Administration on Aging <http://www.aoa.gov/>
 - Administration on Intellectual and Developmental Disabilities <http://www.acf.hhs.gov/programs/aidd/>
- State Planning Councils on Developmental Disabilities <http://www.nacdd.org/site/home.aspx>
- University Centers for Excellence in Developmental Disabilities Education, Research & Service <http://www.aucd.org/>
- Alzheimer's Association www.alz.org
- National Down Syndrome Society/ National Down Syndrome Congress <http://www.ndss.org/><http://ndsccenter.org/>
- National Task Group on Intellectual Disabilities and Dementia Practices www.aadmd.org/ntg

Examples of Community Supports

- Community support provider agencies
 - Private/parent based (e.g., Arc chapters)
 - Public – state/local government entities
- Area Agencies on Aging (AAAs)
 - Aging and Disability Resource Centers (ADRCs)
- Alzheimer's Association chapters
 - Other local dementia care groups
- State and local Protection and Advocacy Networks
- Faith-based organizations
- Statewide or Community-based Respite/Caregiver Coalitions

Certainties vs. Uncertainties

What we can expect...

- Incidence of Alzheimer's disease in adults with Down syndrome is 60% or more
- Average age for onset is 52 some as young as 40s or 30s
- Life expectancy 5-8 yrs from recognized symptom onset
- Mid-stage dementia involves most staff time to manage
- Late-stage dementia changes the caregiving relationship
- Costs increase with dementia care

Certainties vs. Uncertainties

What we don't know...

- Who will be affected
- How long will an individual be affected
- What will be the particular behavioral expressions
- What will be the long-term effects on staff and friends
- What can prevent or slow down progression
- Burn out factors associated with long-term dementia care

Ensuring Healthier Aging for People with ID and Dementia

- Promote a better understanding of people aging with ID and dementia and their needs
- Work to make communities “disability and dementia friendly”
- Assure that services and supports have “quality” as a defining factor
- Promote greater education of personnel
- Involve people with ID and dementia in decision making
- Ensure availability of dementia capable community services and assistance for families

Most Important – Get Diagnosis!

- No cure but medications can help
 - Early diagnosis provides better chance of benefitting from available treatments for symptoms of dementia
 - Medications help treatment of coexisting behavioral changes – psychosis, anxiety, or depression
 - Opportunities for treatment trials
- Allows for adjustments to long term care plans
- Time to develop a relationship with potentially new doctors and care partners

Desired Outcomes

- Maintenance of daily activities and quality of life
- Effective of behavioral and pharmacologic therapies
- Reducing possible LTC placement
- Reducing secondary health consequences including falls, injuries, emergency department/hospital care, polypharmacy
- Reducing challenging behaviors
- Prevention and awareness of abuse and neglect
- Securing supports for families and care providers
- Increased research to find cure
- Awareness of and implementation of economics of care and supports

The Philosophy and Values of Dementia Care

- People are unique
- Maintain and enhance personhood
- Respect for personhood

Thank you!

Cindy Vargo
Central Region Director
Alzheimer's Association
Desert Southwest Chapter
1028 East McDowell Rd.
Phoenix, AZ 85006
602-528-0545
cynthia.vargo@alz.org

alzheimer's  association®

Desert Southwest Chapter

800.272.3900
alz.org/dsw

Research Resources

alzheimer's  association®

trialmatch™

Web Address: <http://www.alz.org/trialmatch>

Phone: 1.800.272.3900

alzheimer's  association®

Desert Southwest Chapter

800.272.3900
alz.org/dsw